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Citation for published version:

Gieben-Gamal, E & Matos, S 2017, 'Design and disability: Developing new opportunities for the design curriculum', *The Design Journal*, vol. 20, no. sup1, pp. 2022-2032.
<https://doi.org/10.1080/14606925.2017.1352721>

Digital Object Identifier (DOI):

[10.1080/14606925.2017.1352721](https://doi.org/10.1080/14606925.2017.1352721)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

The Design Journal

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The Design Journal

An International Journal for All Aspects of Design

ISSN: 1460-6925 (Print) 1756-3062 (Online) Journal homepage: <http://www.tandfonline.com/loi/rfdj20>

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To cite this article: Emma Gieben-Gamal & Sónia Matos (2017) Design and Disability. Developing New Opportunities for the Design Curriculum, The Design Journal, 20:sup1, S2022-S2032, DOI: [10.1080/14606925.2017.1352721](https://doi.org/10.1080/14606925.2017.1352721)

To link to this article: <http://dx.doi.org/10.1080/14606925.2017.1352721>



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Published online: 06 Sep 2017.



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Design and Disability. Developing New Opportunities for the Design Curriculum

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Abstract: Design for Disability has been flourishing as designers and visual communicators attempt to address questions of awareness and accessibility. Despite this achievement, most design courses that address the theme of disability will focus almost exclusively on the functional or medical model of disability, one that locates in the individual a disability that needs to be cured or corrected. In this scenario, less explored is the social model of disability, a model that presupposes an understanding of the factors that contribute toward the disabling of individuals. In response to this challenge, in this paper we will reflect on a course that we have developed in the School of Design at Edinburgh College of Art.

Keywords: disability studies, higher education, design

1. Introduction

Since 2014 it has been UK Government policy that the social model of disability should be used as the basis for interaction with disabled people (Parliamentary and Health Service Ombudsman, 2015; Department for Education, Government Equalities Office, Office for Disability Issues, 2015). Yet public discourse and media representations do not always seem to mirror this shift. Despite the gains made by disability rights activists the medical model and personal tragedy model still permeate the public imagination (Ellis and Goggin, 2015). According to this view disability is located firmly in the individual's own body and individuals are either represented in terms of dependency and care needs or as celebratory examples of individual success in the face of adversity (Beacom, et al, 2016). While critical theory within disability studies has moved beyond the medical versus social model debate to take in a wider set of postmodern theories (Boys, 2014), we argue in this paper that design students should be given a thorough grounding in the social model of disability as a transformative means to counter the pervasiveness of the medical and personal tragedy models or common-sense understandings of disability.

Our attempt to communicate the importance of the social model of disability can be best understood by analysing, in a more detailed manner, the Designing Alternatives (DA) course that we have developed and offered to third-year undergraduate students enrolled in the School of Design at Edinburgh College of Art (ECA). Every year, the course presents a specific topic that we bring to focus. During the academic year of 2015-16 we explored the theme of disability: what it means and how designers and visual communicators might engage with disability issues through their work.

The DA course is an elective course that forms part of the contextual studies component of the design curriculum at ECA. With both a theoretical and a practice-based element, the course offers students the opportunity to practice socially engaged forms of design. Delivered through a mixture of lectures, discussions, seminars and workshops, DA invites students to develop their own projects. Working in groups on a disability topic of their own choosing, in 2015-16 the course encouraged students to employ and develop a range of research skills that are in line with an ethnographic tradition (e.g.: direct observation and interviewing). As part of the students' final submission, they were expected to work as a group to propose some form of design intervention in response to their research as well as submit an individual report reflecting on their research and design proposition. The overall aim of the course was to introduce students to ways of thinking critically about practice-led research that will assist them in their future coursework and professional practice. As such, the course was designed so as to offer students the opportunity to address real-life issues by establishing a direct contact with people who experience those issues in their daily lives.

In response to the challenges that were set by this year's EAD - 'design's response to contemporary shifts in society, technology, production' - in this paper we will explore the social model of disability in relation to the design curriculum and then in relation to our own course. Placing a strong emphasis on the importance of theoretical frameworks in the development of student's critical understanding of disability, later we will explore some of the challenges that we have encountered when motivating students to directly engage with disabled people.

2. Disability and the Design Curriculum

Since the Royal College of Art's pioneering programme on design for an ageing population was first introduced in 1991, followed by the establishment of the Helen Hamlyn Centre in 1999, which sought to develop the theory and practice of inclusive design as a means to address the needs of older and disabled people, there has been a steady growth of interest in socially inclusive design in the UK, of which disability is a key concern (Gheerawo, 2016, p. 322). This has been given further momentum by legislative and regulatory advancements (for example the publication of a new British Standard, BS 7000-6 Managing Inclusive Design in 2005, the Equality Act 2010, and National Planning Policy Framework 2012), as well as the growth of higher education courses addressing inclusive design in UK universities and art colleges. However, even after the success of the 2012 London Games, which was hailed as "the most accessible" Olympic games in history, (Baroness Tanni Grey-Thompson quoted in Office for Disability Issues, 2016) the Government Office of Disability along with the Design Council concluded that inclusive design practices were not sufficiently embedded within professional practice or educational provision; they continue to be an optional extra rather than the norm (Fleck, 2014a).

Moreover, the chief advisor on the Built Environment Professional Education Project which was set up by the Government following the 2012 Games to look into inclusive design in the UK noted that compliance tended to structure the way in which inclusivity was addressed, and while there was evidence of some good practice, students on the whole spent very little time studying inclusive design. This led her to ask, “how many truly understand how disabled and older people use and experience a building or place?” (Fleck, 2014b). Jos Boys, author of *Doing Disability Differently* notes a similar problem:

“Despite many years of campaigning and design effort, the built environment continues to be often inaccessible to disabled people. [...] this is *not* because architects are too egotistical to take disabled people seriously – often what they are accused of – but instead the result of the underlying common-sense conceptual frameworks we *all* use to think about disability, ability, occupancies and material space.” (2014, p.3)

What is striking about these observations is that in the same fifteen year period since the Helen Hamlyn Research Centre was set up, the field of Disability Studies has grown exponentially yet there has been very little cross over between this and the fields of design. Nicole Matthews likewise notes, “the voices of people with disabilities, ideas emerging from the disabled people’s movement and a discussion of processes of disablement, have yet to take a central place in the undergraduate curriculum, outside of the discipline of disability studies itself” (Matthews, 2010, p.527). While this absence of critical engagement with disability studies is not unique to design as discipline, it does seem especially surprising given the shift towards a ‘user-centred’ or ‘participatory’ approach to inclusive design practices. Yet looking at the literature on inclusive design, the discussion of users tends to focus on a ‘tool-kit’ of methods for engagement, in the form of interviews, focus groups, design probes, ethnography etc., (see for example Keates and Clarkson, 2004) without any consideration of theoretical frameworks emerging from disability studies.

Boys, who also observes the lack of critical engagement with disability studies specifically within architectural writing (2014, p.4), raises connected concerns about some of the critical limitations of participatory methods in relation to design for disability. In particular she argues that “in focusing on case-by-case examples – disability becomes a special (and difficult) category that only needs to be dealt with sometimes” (2014, p.140). Moreover, she argues that attention to the “complexities of difference” is undermined by a focus on individuals that are made to stand for an entire category (2014, p.31). These are indeed problematic positions, and underscore the importance of grounding participatory design education in theoretical frameworks drawn from disability studies so as to pull these tensions into focus and provide strategies to mitigate their limiting effects. This theoretical grounding would not only enable students to better understand the contexts in which they are working but would also enable them to extrapolate from the particular to the general and vice versa. Crucially, it would also minimize the likelihood of students framing and interpreting their interactions with users according to their own common-sense understandings of disability.

In contrast to the tool-kit approach of many inclusive design texts books, we would therefore argue that any course addressing design for disability should begin with a theoretical consideration of disability and examination of the different models of disability as developed within the field of

disability studies. Thus students should be introduced to the medical, social model and affirmative models before moving on to wider critical and cultural theory that seeks to break down such binary relationships as abled and disabled. Without this theoretical understanding we suggest that designers will continue to work along a reductive problem solution model that conceives of 'problems' in relation to the 'disabled body' and views that body as 'Other' rather than working to challenge and critique these very assumptions.

Indeed, while the medical model, which locates "disability as an individual problem tied to the functional limitations of the bodies of people with impairments" (Cameron, et al, 2003, p.22), has fallen out of academic and policy favour its grip on the social and cultural imagination, and common sense thinking is still powerful. Hevey, for example argues, "Disabled people are represented almost exclusively as symbols of 'otherness' placed within equations which have no engagement to them and which take their non-integration as a natural by-product of their impairment"(Hevey, 2010, p.332). Design, of course, is not impervious to this and the continuing influence of the medical model on the design of assistive technology in particular is something that Graham Pullin sets out to challenge in his book *Design Meets Disability* (2009). Structured around a series of 'tensions' the book exposes the stigmatising effects that the design of assistive technology can have and explores the ways in which design might move beyond a reductive model that sets disability against the 'norm'. However, while clearly informed by the social model of disability, the lack of explicit engagement with disability theory undermines Pullin's stated goal to demonstrate how "When design meets disability, this meeting will change design itself" (Pullin, 2009, p.307). Indeed, it is even less clear how the design practices of some of the designers interviewed are shaped by anything more than the common sense understandings of disability referred to by Boys. Thus while the book presents a series of thought provoking design opportunities, it also exemplifies our argument that a more explicit understanding of disability theory by designers themselves is needed if these opportunities are to be fully explored in all their complexity. Only then might design really change.

3. From the Medical to the Social Model of Disability

Having set out some of the problems associated with the lack of theoretical engagement with disability studies in design education and practice, in this section we will shift our focus to the social model as a way of unpacking perhaps one of the most important models of disability that we inherit from the field of Disability Studies. In particular, we will explore how we used this model explicitly within the content and delivery of the Designing Alternatives course.

In our first introductory class on the theme of disability, we provocatively asked students to consider their own physical appearance. Drawing on Cameron, French and Swain's *Controversial Issues in a Disabling Society* (2003, p.102), our aim was to foster a reflection on the many ways in which social pressure and stigma might have impacted students' sense of self. To our surprise, students were very keen to share some of the situations and feelings that they had experienced when faced with negative (or, at times, simply inquisitive) remarks or attitudes regarding their own physical appearance. Also in line with Cameron, French and Swaine's approach (2003), we delved a bit further by asking students to consider whether they would ever change anything about their physical appearance. In an era of mass communication, celebrity culture and lifestyle fads where the image of bodily perfection becomes ever more unattainable, it was no surprise to find a number of students confessing a desire to perfect their bodies. Interestingly enough, and as our conversation in smaller

groups progressed, we discovered that the idea of perfecting one's image was often influenced by how students imagined that they would be perceived by others; something that is explored in the Disability Studies literature as well (Cameron, et al, 2003, p.22).

Following this discussion, the students then agreed with Cameron, French and Swaine's idea that: "our perceptions and experiences of reality are informed by particular models and frameworks that reflect dominant practices within particular societies and cultures" (2003, p.20). In that sense, our discussion led to a conclusion that resonates with the authors' statement that: "our body is socially constructed or created and how we think about our bodies depends on the social, cultural and historical context" (2003, p.102). Furthermore, Cameron, French and Swaine's contribution echoed Shakespeare and Watson's (2002) controversial idea that 'everyone is impaired' in that all of us can, when prompted, sympathise with the fragility of human experience when we are asked to reflect on our own limitations and desire to conform to social and cultural norms and conventions.

As the reader can conclude from the thoughts that are shared above, the method of interaction, whereby questions regarding one's own body are posed to the class as a matter of debate, constituted an effective method for enabling the students (who experience forms of disability, or not) to gain insight into the many negative experiences that disabled people experience on a day-to-day basis. More importantly, the conversation that we collectively established with students in class allowed us to tap into the many 'disabling expectations' (French, 1994 in French and Swain, 2004) that are socially constructed depending on the situation or cultural norm. People with physical and cognitive impairments will face great pressure throughout their lives as they are coerced to conform to a multitude of norms. Using here French and Swaine's (2004) own key words, disabled people are too often pressured to be 'independent' despite one's need for care, to be 'normal' despite one's possibility to express their character in a multitude of ways, to 'adjust' to constricted and unfriendly spaces and to 'accept' one's situation despite the possibility to strive.

Our way of presenting the social model of disability allowed us to tap into the many ways in which people are forced into a situation where they experience disability due to the restrictive nature of their physical surroundings, environment, social attitudes and culture. In line with design - and perhaps a more object - orientated way of thinking - the social model of disability set a new path for the class to consider disabling environments, objects or social and cultural contexts as opposed to disabled individuals. This shift in understanding, provoked a profound conceptual shift in students understanding of disability as a whole. This shift was also supported by our analysis of Sunaura Taylor and Judith Butler's conversation for *Examined Life*, a documentary produced by Astra Taylor. In this conversation, Sunaura, a disability rights activist, provides an eloquent examination of what Cameron and colleagues have named as 'disabling expectations' (French, 1994 in French and Swain, 2004), stating the following:

"Well, we're very culturally engrained early on to move in certain ways, to walk in certain ways, to gesture in certain ways. And for me it's very interesting to think about what it means to be born in a body that can't physically move in culturally accepted ways, and you have to design your own movements" (Taylor, 2008).

With the words of Sunaura Taylor, we proceeded by focusing on Shakespeare and Watson's (2002) emphasis on the importance of barrier removal versus a focus on medical intervention and rehabilitation. Our focus should not be understood here as a disregard for the medical model or the

importance that it has in framing disability. Indeed, we continued to stress to students the fact that “people with different impairments experience specific issues and problems, both medical and social” (Shakespeare, 2006b, p.32). Rather, our attempt to contrast the social model and the medical model was a way of highlighting how one model defines people in terms of physical impairments (disability is a physical and/ or mental fault that can be located in the individual) while the other focuses on how people can be disabled by their environment. As well as thinking about physical barriers we also used the film to discuss representational barriers as well as the social norms that define how our bodies are constructed through culture and how this reinforces ideas about what is ‘normal’ and ‘abnormal’.

From an educational point of view, contrasting the social and the medical model was an enriching process considering that it prompted an understanding of ‘disability as a complex phenomena’ (Shakespeare, 2006a, p.203). This idea echoes the work of Corker and French (1999, p.6) as both authors contend that: “the distinction between biological/ individual impairment, and social/ structural disability is conceptually and empirically very difficult to sustain”. Looking at the work of Wall (1999), our way of contrasting both models of disability was in line with the idea that “Pain itself is generated through the interplay of physiological, psychological and social-cultural factors and thus the individual experience can never be separated from the social context” (Shakespeare, 2006b, p.34). It was the importance of the social context that we wanted to emphasise; not only to question the prevalence of the medical model, but also to encourage the production of design interventions that are situated within a broader and more complex understanding of disability.

4. Learning Through Direct Contact with Disabled People

While the course was grounded in a theoretical consideration of the key models of disability our invitation to students to consider their own experiences, in relation to the theories we were discussing, was informed by an ethnographic tradition that promotes modes of self-reflection (see for example the work of Goodley, n.d.). Further to this, we also felt it was vital that the voices of disabled people should form a central part in the course both in terms of its delivery and as part of the students’ own fieldwork. In this final part of the paper we will analyse in more detail these elements of the course.

As outlined in the introduction, the students were required to identify, and work in groups on a project of their own choosing employing and developing a range of research skills that are in line with an ethnographic tradition. The brief itself required students to identify an ‘object’ (this could include a building, interior space, urban space, service, film, installation, garment, wearable, a textual or visual piece of communication, etc.) through which they could explore the issue of VISIBILITY / INVISIBILITY as it applied within the context of disability studies. Student groups were then expected to propose some form of design intervention to readdress the issues that were identified.

Following the initial sessions on the theoretical context of the course the remaining sessions were directed toward a presentation of ethnographic research methods; a discussion of research and ethics; and a guest lecture session in which we invited a guest speaker, George Low, founder of the University of Edinburgh’s disability research network — ‘Disability Research Edinburgh’ (DRE) — to

come and present his research to the students. A wheelchair user as well as a PhD researcher, our guest also assisted us in the design of the lecture on research and ethics by introducing students to the importance and significance of language through a list of 'acceptable' and 'unacceptable' terms relating to disability and that should be kept in mind when interacting with a disabled person. This list was used to prepare students for fieldwork where they would be in direct contact with a disabled person or group of people.

The list of acceptable and unacceptable terms served as an entry point into a more personal conversation whereby our guest speaker chose to describe situations where he himself had experienced forms of social exclusion based on his use of a wheelchair. It also provided an entry point into his own intellectual frustrations with the medical model of disability. Coupled with the students' use of ethnographic research methods when researching in real life situations, our guest's talk gave a personal voice to a topic that would otherwise be explained through a purely theoretical lens. Echoing observations made by Matthews and others as to "the radical and transforming effect of the presence of disabled teachers in the classroom" (Matthews, 2010, p.531) student feedback on the course suggested that this 'personal voice' provided a particularly enriching learning experience.

However, while George Low's participation greatly enhanced the course, inviting a disabled guest speaker to contribute to the course delivery also raised ethical issues for us. In particular, we wanted to avoid any sense of tokenism, or inference that our guest speaker should be expected to expose his body to the scrutiny of students. As one disabled teacher wrote:

"I do resent any inference that the mere fact of my disability augments my teaching qualifications or that there is a pedagogical value in exposing my disability to nondisabled students. This practice smacks too much of the freak show and casts me in the role of goodwill ambassador sharing the quaint beliefs and customs of my alien world." (Quoted in Matthews, 2010, p.531)

As such our guest was introduced in relation to his doctoral research on disability and while he was happy to discuss his own experiences of disability the session was not framed around his own body. Nonetheless, one of the students, perhaps due to the safety and familiarity of the surroundings, asked a question that was typical of the kind of intrusive questioning that serves to "frame disabled people in ways they themselves do not recognize" (Boys, 2014, p.13). While our guest, with great elegance and generosity of spirit, used this opportunity to talk more about the disabling attitudes of abled people, following on from his discussion about the power of language, it nonetheless flagged up the need for greater discussion about the ways in which attitudes towards disabled people revealed in everyday engagements often create greater barriers than the impairment itself. As Boys writes, "Impairment, then, is not a neutral or objective fact; it is made and remade through everyday feelings, experiences and encounters." (Boys, 2014, p.12)

Our anxiety about the students' interactions with disabled people was also felt by the students themselves as the course brief allowed them the freedom to set their own topics and to conduct fieldwork. These anxieties were alleviated to some degree by the session we delivered on research ethics and through the completion of a compulsory ethics checklist by each of the students, as

required by ECA, but we were nonetheless aware that there was still scope for students to ‘get it wrong’ when engaging with disabled people. However, when set against the benefits of engagement we would argue that the potential limitations of short ethnographic fieldwork and the ‘managed risks’ associated with it were worth taking. First and foremost, by engaging with disabled people directly, their voices became central to the students’ learning rather than peripheral to it or silenced. This seems particularly important in a field where the voices of disabled people, whether as designers or users, are rarely heard. Secondly, the anxiety or self-criticality around language as identified by students on the course was also a vital part of the learning experience, serving to demonstrate how everyone is locked into discourses around disability, if not directly through the experience of disability itself, then through the privileged position of ableism (Matthews, 2010, p.532). Finally, while designers in their professional careers may be more likely to work in interdisciplinary teams, where ethnographic research is carried out by professional ethnographers, we would argue that students’ direct engagement with disadvantaged groups at this formative stage in their design careers is vital if design’s bias towards able-bodied consumers is to be effectively challenged. For it was through working with disabled people that the students’ preconceptions of disability as something that is ‘Other’ was challenged and they came to understand and experience it as something that is produced through a complex web of social, cultural, political, economic and physical conditions in which everyone is embedded.

5. Concluding Thoughts

Looking back on the course one of the most striking aspects of it was the number of students who either drew on their own first-hand experience of disability or had close friends or family with direct experience. This, and the time limitations of the ethnographic research element (given the whole course was delivered over ten weeks), led many students to work with people they knew or with whom they already or had some connection. Perhaps more than anything, this served to demonstrate how design for disability is not the niche, or minority, subject some students first thought. More importantly, direct contact with disabled people, both within and out with the classroom had the power to transform the social model of disability into a more tangible and lived concept for the students. As lecturers and course organisers, this experience also taught us that theory is vital to the development of courses that tackle design for disability.

Taking into account the profound transformation that the social model of disability had on our students, we would like to finish our contribution by emphasising the importance of both theory and practice in the education of future designers. Writers and educationalists, such as Boys, have criticised the idea that disability should be positioned as an ‘add on’ to architectural and design degrees which might mitigate against the provision of discrete courses on disability which, it could be argued, merely serve to maintain disability’s marginal status and do little to alter the status quo. However, Boys’ particular criticism seems to focus on a compliance-based approach to disability, which she suggests is characteristic of architectural degrees (2014, pp.4, 23), rather than on courses that seek to expose and critique the ways in which disability is framed, socially, culturally, politically and, crucially here, through the built environment and material world. Boys also argues persuasively that courses such as these should move beyond the medical and social models of disability to take in postmodern identity theory and post-humanist theory which serves to further problematize what it is to be dis/abled. While we would fully agree with this we might seek to temper her analysis that aligns the social model with a compliance-based approach to design (2014, p.25). While the social model of disability may have provided the stimulus for better regulation, which has in turn led to a

compliance-based approach in architecture that lacks criticality about the environment that is being built, we suggest that this is not an inevitable outcome. Indeed, the social model can provide a powerful way of critiquing normative ideas and values as well as those of the medical model as it too has dominated ideas about design – particularly with regard to assistive technology and inclusive design. Thus, while postmodern theory should form an important part of higher-level courses, we would make the case that the social model provides an important first step in identifying and challenging these theoretical constructs. Moreover, to do this in a rigorous manner that enables students to learn and understand the theory and then to embed it in their practice, requires discrete hybrid courses that have as their main focus the question of disability. Thus we suggest that the work presented in this paper can be understood as a starting point for a new way of thinking about design for disability, and an educational model that supports this, working to push the boundaries of our own frames of references both within and beyond the field of design.

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Acknowledgements: We would like to first thank the School of Design at Edinburgh College of Art for supporting the Designing Alternatives course. Our grateful thanks to the students that have attended the course during the academic year of 2015-16, their feedback and participation in class has informed the way in which we have shaped the

course as well as our own understanding of the role of critical theory in the design curriculum. Finally, a special thank you to George Low who has contributed to our guest lectures and who has provided constructive recommendations on the Designing Alternatives project as a whole.